

BREAKING GROUND



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"Miracles do include the sun rising, but there are smaller miracles. Some of my miracles have included regaining speech, walking again and drinking iced beverages without choking."

— Bernie Goggins



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DOING IT

A Commentary by Bernie Goggins

It is the doing that is the critical component. We, as TBI [Traumatic Brain Injury] survivors, have no choice except to change and adapt our methods in recognition of the limitations imposed by our injuries. Our minds are constantly active, solving problems that are restricted to our unique conditions. There are rare survivors who have the ability to recognize the miracles in which we are involved every day.

Miracles do include the sun rising, but there are smaller miracles. Some of my miracles have included regaining speech, walking again and drinking iced beverages without choking.

Your list may not show similarities in the specific 'its', but you have a list of 'its' that recurs each day. The 'its' are not the concern here, but the recognition of each 'it' and an associated adaptation that accomplishes 'it' is the concern.

I feel that we survivors are lost in thinking:

1. No one has ever experienced this before.
2. No one can show me a solution for this.
3. This is too simple to justify asking for guidance.

Our injuries imposed and continue to impose limits on the single tool that allows recognition of the former routine, current restrictions preventing the execution of that routine, and possible alternative executions that will accomplish the goal.

Survivors are generally and frequently recognized as different, but indescribably different. Our problems in constructing meaningful thoughts are generally and frequently thought to be permanent and the help we are offered is to adapt to the new restrictions. There is no recognized potential for improvement of brain injuries. The damage is unlike a broken bone where mending occurs with casting and inactivity; the brain does not improve with casting and inactivity.

The acceptance of that logic is a significant interference with our recoveries. The literature does not recognize improvement as a potential. The literature indicates that acceptance is the only action possible after a brief period of adjustment. Our injuries insist that we enter a recuperative program of thinking. Most caregivers try to pretend the care of a fracture is appropriate and will allow healing. There is no recognition that thinking is the therapy of choice.

I have a limited study group: me. That is not statistically significant; it only involves one individual. It is an individual with a severe TBI who was in a coma for a month and had additional injuries, but it is a single individual.

He has broken nearly all of the accepted principles and he thinks a single success is adequate reason to alter years of research?

Yes, I do. The research previously completed has largely involved acute injuries and autopsies. When some indication of thought was displayed, that was thought to be the totality of possible recovery. Those of us who have demonstrated non-acceptance and improvement can only be flukes and aberrations. The research cannot be in error.

Acceptance is not success. Accepting a severed spinal cord is recognition of the reality of the inability to sense or control beyond the level of injury. It does not prevent higher activities. Examples of genius among those in wheelchairs are often seen. Franklin Roosevelt and Stephen Hawking are noteworthy examples. Their problems were polio and ALS [amyotrophic lateral sclerosis], not TBI.

Their regimens of care did not exclude thought and both demonstrated profound intellects. Both also lived beyond expectation. My mother and father are in their eighties. In February of 2009, Mom will be ninety. They both remain mentally active and do crosswords, word finds and other mental exercises. They recognize at some level the need to stay mentally active to stay alive. They are doing, they are thinking, they are surviving, they are succeeding.

In the time it has taken to write this, my study group has grown to five. My mother and I are not using wheelchairs. Dad, President Roosevelt and Dr. Hawking are or did use wheelchairs. I may be the youngest at age 60, but we all demonstrate significant survival and success.

My study of doers and thinkers remains statistically insignificant. It is 100% successful on five individuals, but the individuals were not selected randomly. They share specific characteristics. Are not all study groups selected because of shared characteristics?

Bernie Goggins, of Knoxville, is a prolific writer, whose articles can be read at www.bluelangroup.com/bernie.

WHAT REUTILIZATION MEANS FOR TENNESSEE

BY MEGAN HART & SHERI GRIGSBY

Anna spends much of her time in front of her gently used Closed Caption Television (CCTV), which is located in the computer lab on the ground floor of her East Tennessee low-income housing unit. Donated by the local contracted Tennessee Technology Access Program (TTAP) center, this assistive technology helps Anna continue her research interests and allows her to read her religious materials. These things have become increasingly hard for her since the progression of vision loss.

Anna also helps others in her building to use the equipment. She feels more productive and happy with the addition of her CCTV and being able to fulfill the needs of those around her. This is only one of the many examples of individuals who can benefit from reutilized equipment that others have decided to throw out.

Given the current economic strains and rising cost of health care, there is a growing need for us to make the most of our resources. In response, TTAP, in conjunction with its five contracted assistive

technology centers, is creating a statewide reutilization network. Reutilization involves cleaning and matching used assistive technology devices and durable medical equipment to new consumers and disposing of end-of-life recycled pieces of equipment.

By establishing open communication between agencies across Tennessee, TTAP's goal is to create a boundary-free avenue that increases access to used equipment for Tennesseans who may not have the means to acquire the tools they need, while, at the same time, keeping those older yet usable devices out of our landfills. TTAP's statewide network will include agencies throughout the State that operate reutilization programs or have an interest in participating in the effort. This will include larger partners, such as universities and State government programs, and smaller community agencies, such as faith-based organizations, civic groups and nonprofit entities, interested in combining and sharing resources and services.

TTAP took the first step in promoting a statewide network by hosting a conference on November 7, 2008. Participants included representatives from several universities, five Centers for Independent Living, Goodwill Industries of Middle Tennessee and Chattanooga, as well as churches and agencies currently involved in the reutilization of durable medical equipment. The conference, attended by nearly 60 people, provided both networking opportunities and information, helping attendees to better understand how they can collaborate with each other and expand into a statewide network of reutilization programs.

The conference was kicked off with an informative presentation by keynote speakers Carolyn Phillips and Liz Persaud from The Pass It On Center in Atlanta, Georgia, a national reutilization resource center. Attendees also participated in networking table discussions, listened to two of TTAP's contracted assistive technology centers describe their partnerships with local agencies, and brainstormed about other collaboration opportunities in their own parts of the State.

As a result of ideas shared by conference goers, TTAP will be helping to facilitate the development of more regionalized collaboration activities to ensure additional





Joan Guy

agencies have the opportunity to learn about and connect to the network. The AmeriCorps VISTA members that TTAP has at its State office and at four of the five contracted assistive technology centers also will help expand the reutilization network by communicating with each other and local agencies in their regions to effectively link potential partners together.

The assistive technology centers have operated the TTAP reutilization program by discovering and accessing the resources of a variety of sources, including individual donations, recycling programs, government surplus and devices formerly used in other service programs, and distributing that equipment to individuals with disabilities at no cost. Operating as a network will allow the assistive technology centers and partnering agencies to meet the needs of additional individuals and families in a more organized and efficient way. For example, if a person interested in acquiring a computer through an assistive technology center also needs a bath bench, the individual will be able to more easily acquire both

pieces of equipment through different partnering agencies. Finally, the more agencies that become involved in the statewide network, the easier it will become for individuals with disabilities to access needed equipment during emergency situations or in times of need.

Obtaining assistive technology or durable medical equipment frequently increases the opportunities for individuals with disabilities to develop careers and participate in their community. This equipment may be unobtainable because of financial constraints, lack of availability in rural communities, or lack of awareness and knowledge of knowing what is needed and how to obtain it. With a network of agencies, services and resources, the reutilization program can put equipment in the hands of individuals with disabilities in order for them to lead fulfilling lives.

Megan Hart is funding specialist & SAC liaison with the Tennessee Technology Access Program; Sheri Grigsby is Vista liaison with the Tennessee Technology Access Program.

CELEBRATING LITERACY

BY SHERI GRIGSBY

Early one sunny morning in 1812, three-year-old Louis wandered from the house into his father's workshop where he enjoyed watching harnesses and saddles being made for the horses of his surrounding village. On this morning, however, his father wasn't working quite yet and Louis, being a curious boy, began playing with the sharp instruments nearby. A tool used to cut leather slipped from his small hand, landing in his eye.

Blinded by the accident, this curious little boy, born just outside of Paris, France, would begin to use shapes cut from leather to create his own version of a raised language for reading by touch. This begins the story of one of the most famous blind leaders in history and the reading method we call Braille.

Now, as I sit with my two daughters, a book open between us, I reflect on the January 4, 2009, bicentennial commemoration of the birth of this creator of the Braille code which has given children and adults who are blind the ability to become literate. I am reminded of that small boy and his impact on my family.

Blind since birth, I am able to use Braille daily, reading my children's bedtime story, preparing dinner from a recipe, keeping tabs on shopping lists and appointments, and identifying labels placed on household equipment. Braille has enabled me to become employed, not just by adding the ability to read notes and office correspondence, but also to read bus schedules and more rudimentary things needed to retain employment. Most of all, I am able to convey to my girls the importance of the right of all people to learn to communicate with one another.

The United Nations Educational, Scientific and Cultural Organization (UNESCO) describes literacy as "a continuum of learning to enable an individual to achieve his or her goals, to develop his or her knowledge and potential, and to participate fully in the wider society."



Braille literacy should not be interpreted any differently. The phrase "participate fully in the wider society" encompasses more than the ability to read a book from the library. A child gaining the knowledge needed to participate fully in classroom activities, while important, isn't the only skill gained by learning to communicate his or her thoughts to others. Extra-curricular activities, such as participating in the drama club or learning to play an instrument in the school band, give the child a sense of belonging and help foster a sense of ownership in his or her life choices. Children learning to communicate thoughts to teachers, friends and family, growing into adults using their literacy skills to obtain meaningful employment, not only adds to their family's income and overall feeling of accomplishment, but will facilitate economic growth for our country.

Currently, there seems to be a debate among educators, consumers and professionals in the blindness field as to the importance of continuing to produce Braille. The argument, if it can be called such, seems to be rooted in how effective audio and computer-based literacy is for the child or adult with a vision loss. To accurately produce Braille, there has to be extensive knowledge of the Braille code, how to use the Braille embosser and accompanying translation software, and the production cost is quite expensive. This has led to much weighing of audio and computer literacy versus training and production costs, as most audio and computer-based literacy is virtually free.

In my unprofessional opinion, there is no comparison. While audio is an extremely efficient method of capturing large textbooks, and I was able to use them in college, it is not the same as actually reading the written words. My retention of materials obtained by listening has never been as great as my retention of reading them for myself. The difference between reading and listening was never more apparent to me as an adult than while participating in the 2006-07 Partners in Policymaking™ Leadership Institute. I was provided all materials in Braille, to my sheepish surprise, including the

Braille version of the PowerPoint from each presenter. I had in front of me what everyone in the room was looking at on the overhead. I found myself more connected to not only the presenter, but the room at large. Asking questions and participating fully in the workshops proved to be greatly enhanced by the Braille materials.

As an adult, Louis Braille became a teacher at the Royal Institution for Blind Youth in Paris and was able to have an impact on the children he so desired to give communication. The first Braille book was published in 1827, but there was extreme opposition to children being taught the system. Louis Braille died in 1852 without his creation of literacy by touch being fully accepted.

Today, thousands of children and adults, with varying degrees of vision loss, use Braille to communicate just like my family does. To me, literacy is and should be taken very seriously, if we are to create an inclusive society. Please join with me in celebrating this

important year, not only as the anniversary of Louis Braille's birth, but for the impact his intelligence and tenacity has had on an entire community of people.

***Editor's note:** This year, the United States Mint is producing the 2009 Louis Braille Bicentennial Silver Dollar to commemorate the 200th anniversary of the birth of Louis Braille. For the first time in history, a United States coin features readable Braille.*

Surcharges from sales of the 2009 Louis Braille Bicentennial Silver Dollar are authorized to be paid to the National Federation of the Blind to further its programs to promote Braille literacy.

Sheri Grigsby is a member of the Tennessee Council on Developmental Disabilities.



In May of 2000, Goodwill HELPS, which stands for Health Equipment Link Program Services, was formed with the vision of providing durable medical equipment to individuals in need. HELPS received a national award from Goodwill International in 2006 for Excellence in Mission Advancement, and was awarded the Robert E. and Charlotte Watkins Award.

Signal Centers' Assistive Technology (AT) Center, a member of the Tennessee Technology Access Program's (TTAP) assistive technology network, has had a reutilization program for durable medical equipment and assistive technology since 1991.

In 2006, Signal Centers and Goodwill HELPS formed a partnership to further improve the strengths of each program and expand the reach of both. This partnership has not only improved access to a larger pool of devices for those who need them, it has proven to be a successful model of collaboration for others who choose to join the TTAP Reutilization Network.

With a shared commitment and a mutual promotion and referral system, Goodwill HELPS and Signal Centers' Assistive Technology Center obtain and distribute both free durable medical equipment and assistive technology throughout Southeast Tennessee and, in the process, have changed the lives of many individuals.



TRAINING JUDGES AND ATTORNEYS:

DISABILITY AWARENESS AND SENSITIVITY IN THE COURTROOM

BY COURTNEY TAYLOR

Administrative Law Judges
who conduct special education

mediations and due process appeals are required to undergo annual trainings in special education law and disability-related issues. In 2007, psychologists and special educators from the Vanderbilt Kennedy Center conducted a training session for judges in Tennessee that included overviews of IDEA (Individuals with Disabilities Education Act), developmental disabilities, and assessment services and procedures related to developmental disabilities. In 2008, the training became a bit more specialized.

"Autism is probably the most common disability seen by our judges in the IDEA cases filed with the Administrative Procedures Division [APD]," said Thomas Stovall, director and Chief Administrative Judge of the APD. "As judges hearing these cases, we need to know what autism is. We need to understand that it is a spectrum, and that it can look different in different people. We need to know about assessment and treatment options. We thought an entire day of training on autism would be very beneficial. It certainly was."

The autism training for the judges was led by Evon Lee, PhD, associate professor of pediatrics, and Courtney Burnette, PhD, clinical assistant professor of psychiatry. Both are psychologists with the Vanderbilt Kennedy Treatment and Research Institute for Autism Spectrum Disorders (TRIAD). Drs. Lee and Burnette trained 32 judges from Tennessee, North Carolina, South Carolina, Michigan and Minnesota with a focus on diagnosis, assessment and intervention, as well as "hot topics in autism".

"We tried to illustrate the spectrum of autism spectrum disorders," said Dr. Lee. "We wanted to broaden their perspectives and give them concrete examples of what these kids look like. We talked about 'hot topics', about the way autism has been portrayed in the media. There's a lot of hype out there, and we wanted them to understand that they should be very cautious and take an evidence-based approach. We wanted to be sure they knew to look carefully and not just get swept up by the media frenzy."

The assessments section of the training included demonstrations of some of the toys and tools that psychologists use when administering the Autism Diagnostic Observation Schedule (ADOS). Having a tea party, blowing bubbles and shooting balloons across the room gave judges a concrete view of what an actual assessment looks like. "It sounds silly to think of law judges watching bubbles float around the room," said Dr. Burnette. "Yet, it showed them exactly what we do. Rather than it being a vague diagnostic instrument we just talked about with them, that portion came to life and gave them insight into what a child might experience during an assessment."

Drs. Lee and Burnette both expressed an appreciation for the difficult position the judges are in as they hear the IDEA cases. Balancing the needs of a child with what the law says, and at times in the context of distressed parents who only want what is best for their child, is not an easy task. So the training provided an opportunity for them, as psychologists, to paint a clearer picture of what families experience as they receive a diagnosis, navigate through treatment options or receive confusing messages from the media.

"When I do an evaluation, I feel like I touch one person's life," said Dr. Lee. "Doing trainings like this presents wonderful opportunities to reach even more families. These judges go across an entire state, so you have the potential to have a little impact on a lot of people. We are providing them with information that ultimately impacts the families we are working with in very different ways."

TRAINING ATTORNEYS

The Vanderbilt Kennedy Center and The Arc of Davidson County recently partnered to train attorneys interested in working with families who are considering going to due process or who are having trouble accessing services within their school district. Relatively few attorneys in Tennessee specialize in special education law, and for those who have this area of expertise, the cost of their services may not be affordable for many families.

In 2007, Erin Richardson, director of the Legal Advocacy Project for The Arc of Davidson County, set out to remove these obstacles by recruiting lawyers working in other areas of law and developing a training program to educate them on special education law matters. "The training was developed to build a larger base of attorneys who are educated in special education law and who can represent families on a pro bono basis," said Meghan Burke, the training coordinator and a doctoral candidate in special education at Vanderbilt. "We ask the attorneys to commit to working with one family who is considering going to due process. Erin works with many families, and building this base of attorneys allows her to make referrals confidently. And it is not an overwhelming commitment on the part of the attorneys because, generally, he or she can meet with the family and the school district and hammer out the issues before going to due process."

For information or to participate in the attorney training contact meghan.m.burke@vanderbilt.edu.

Courtney Taylor is associate director of Communications and Dissemination at Vanderbilt Kennedy Center

Q&A

Q & A WITH BOB DUNCAN, DIRECTOR OF THE GOVERNOR'S OFFICE OF CHILDREN'S CARE COORDINATION

BY MEGHAN BURKE

BG: Can you define your role as the director of the Governor's Office of Children's Care Coordination?

BD: I came to this position at the end of July. I have the pleasure of working with a great group of people to coordinate services with State agencies and community providers for children to receive appropriate services. Our agency works for all children, not just those with disabilities. Our team is diverse and unique with everyone having a talent and passion for children with disabilities. We have a pediatrician, women's health researcher, women's health director and epidemiologist, among other positions as a part of our team.

However, we are making a lot of efforts with children with disabilities to get them more resources. For example, we have a steering panel working for families of children with autism. We brought in a group of people from all walks of life that have a role or impact in autism—parents, educators, TennCare staff, health experts and DCS [Department of Children's Services] employees. We bring them together so we can discuss ideas and opportunities to improve services for these children.

BG: Can you describe the governor's involvement in your office?

BD: We cannot be more thankful to our governor and his dedication to children. He created this office in 2004. He really paved the way as not many other states have an office like this—one that is devoted to children. The governor constantly asks about our opinion of services and how to improve services for children. He has a tremendous vested interest in good, appropriate coordinated care so parents have what they need to provide services to their children.

BG: What does a typical day look like for you?

BD: I can't say that I have a typical day. Really, my routine varies. Next week I am going to Memphis to visit with the mayor's office, hospital officials, etc. Today I have budget and staff meetings.

I travel all over the State to help children living in each region of Tennessee. We don't take a cookie-cutter approach here to helping children. We realize there are different issues which affect children in various areas. We know that Tennessee is very different demographically across the State. So we try to have a grassroots effort by asking local and State agencies what they think the problems and solutions are in their area of expertise.

BG: What is your vision or expectation in this role?

BD: I hope to maximize the resources we have, look at ways to improve those resources and opportunities that we need to provide, and make an easier transition for children with special needs for better health outcomes. By transition I mean shifting from high school to adulthood, providing healthcare from pediatrics to adults, and supporting children in State custody to independence.

BG: What work were you doing before this position?

BD: Prior to this, I worked for LeBonheur Children's Medical Center for 14 years. The medical center is in West Tennessee. Also, I have a daughter who has spina bifida. Being a parent of a child with a disability was an eye-opening experience for me. So, I started seeing everything I did from a different perspective.

Then, I began working at the hospital because of the compassion I had for children. I started working for children realizing how much I learn from them myself. I am trying to make a difference in the life of a child because of the amazing difference in my life they have given me. I watch the obstacles that they have to overcome to do what a lot of us take for granted. Watching them work through their efforts is very inspiring. It makes me want to work harder for other children with disabilities across our State.

Meghan Burke is a doctoral candidate in special education at Vanderbilt University and a member of the 2008-09 Partners in Policymaking class.

HEALTHY AND READY TO WORK!

BY CAROL WESTLAKE

"Transition" is a hot topic in the disability community, and appropriately so.

Children grow into youth and eventually blossom into adulthood. All parents and communities want children to grow into adult lives of independence and self-determination.

Transition activities for children and youth with disabilities often are focused on the move from educational services to postsecondary education or employment. Less often, parents and professionals think about health care transitions. According to the American Academy of Pediatrics, the major areas of health care transition include moving from child and family-centered pediatric care to adult-oriented medical care, the school environment to the workplace, and living at home to community living.

Success in the classroom, within the community and on the job requires that young people with special health care needs stay healthy. To do so, young people need to understand their health care options and have greater opportunities to participate in their health care decisions as they age.

The childhood of children and youth with special health care needs often has been characterized by greater dependence on their parents and other adults. As a result, youth with developmental disabilities or chronic illnesses often miss the natural adolescent processes and experiences of their typical peers. Without deliberate planning, young adults may not develop the skills necessary to manage their own health and well-being.

Reaching the age of majority puts many youth in jeopardy as they move from services based on entitlement to those adult services that are not. He or she may no longer be eligible for the same health insurance, access to pediatric specialty clinics may no longer be available, and adult health care services will not have the family-centered feel of most pediatric services. Too often there is little or no planning to cope with these dramatic changes.

Although these changes can have a significant impact on the availability and quality of care, a recent survey conducted by Family Voices of Tennessee and the Vanderbilt School of Nursing found that only 48% of providers had discussed these changes with the patients and families of those who responded to the survey. Only 44.9% of teachers had discussed transition issues of any type with parents.

In response, Family Voices, a program of the Tennessee Disability Coalition, has developed a new project, *Healthy & Ready to Work*. The project, led by Julie Sullivan, is designed to help families and physicians facilitate smooth and effective transitions from pediatric

to adult health care for children and youth with special health care needs (CYSHCN).

A pilot project, funded by the Baptist Healing Trust, is focused on Davidson and surrounding counties. The pilot will allow Family Voices to develop the resources to provide pediatricians and pediatric specialists with the tools they need to partner with families in these transitions. It will develop a model to empower CYSHCN and their families to plan and carry out the changes necessary for effective transition.

Family Voices seeks to increase the core knowledge and skills of pediatric providers, parents and youth, and to teach skills to families and youth through training and individual assistance. Transition to adulthood for CYSHCN needs to begin early and must be supported by an integrated system of care. For that reason, it is critical to work with all partners—pediatric providers, parents and youth—to make this happen. Youth with special health care needs know what it is like to be on the receiving end of services: medical treatments, education, mental health, social support and related programs.

Providers and agencies have gotten better about including family representatives in their program planning, needs assessment and evaluation of services to assure family-centered practices are an integral part of implementation. But what about the person at the center of these services—the youth?

Healthy & Ready to Work takes to heart the saying, "Nothing about me, without me!" by placing its focus squarely on developing the understanding and health care management skills of youth and emerging young adults who are seeking greater independence. A healthy and successful future depends on it.

For more information, contact Julie Sullivan at 888-643-7811 or 931-212-5557.

Carol Westlake is executive director of the Tennessee Disability Coalition.



Julie Sullivan

Photo by Cathy Randall

FAMILY VOICES of Tennessee
part of a national grassroots network of families and friends
speaking on behalf of children with special health care needs



ISOLATION AND RESTRAINT IN SCHOOLS— “WRITING” THE RULES “RIGHT”

BY SHERRY A. WILDS

Effective January 1, 2009, children with disabilities have some protection in the law against unnecessary and unsafe isolation and restraint in school. Unfortunately, reports of children with disabilities in Tennessee being locked in closets for entire days at a time, put in small plywood structures, tied to chairs, and seriously injured while in school settings made the passage of this law necessary to make sure our children with disabilities are safe at school.

Last May, the Tennessee legislature passed *The Special Education Isolation and Restraint Modernization and Positive Behavioral Supports Act*, which can be found at TCA 49-10-1301 et seq. However, the rules that serve as the “playbook” for the new law have not been finalized yet. It is these rules that we hope will clarify the law and fulfill its intent so that children with disabilities are physically and emotionally safe while at school.

Some of the provisions of the new law prohibit certain practices in schools or require specific steps if a child is restrained or isolated. For example, the law forbids the use of locked doors or of physical barriers to lock a child in a room or structure. A child who is placed in isolation must be within constant view of a staff member and all forms of isolation and restraint must be reported to the school principal, who must document the incident. Parents may view this report on request. Emergency restraints that are not part of the child’s Individualized Education Plan (IEP) must be reported to the parents.

In addition to these provisions, the new law requires the school to do a manifestation review before filing a juvenile petition against a child. A review team would have to decide that the behavior was not caused by the child’s disability before filing a juvenile petition. Several other restrictions and requirements are addressed in this law which can be viewed at the Disability Law & Advocacy Center’s (DLAC) Web site: go to www.dlactn.org and click on “useful information” and then click on “education information”.

Despite the requirements in the new law that seem to offer some level of protection for children with disabilities in school, more can be done through the rulemaking process to explain how to implement these provisions. The Disability Coalition on Education (DCE), a family-driven statewide coalition made up of families, educators and advocacy agencies, including DLAC, worked closely with The Arc of Tennessee in drafting the bill that was later amended and passed.

Recently, DCE submitted written public comments on the proposed rules. In these comments, DCE expressed particular concern that the rules, as proposed, did not go into enough detail to carry out the intent and specific mandate of the law. Some “Guidelines” also were proposed; however, these do not carry the weight of rules and still did not address the gaps in the law. Fortunately, the State Board of Education agreed to extend the public comment period to November 24, 2008, and to postpone the first reading of the rules to January 30, 2009. This gave DCE and other groups some more time to develop comments on the rules and to plan to attend meetings of the State Board of Education.

Advocacy groups have expressed concern that the proposed rules do not provide enough direction for schools and families. For example, definitions of types of restraint, isolation, timeout and positive behavioral interventions need to be clearer and provide more protection for children with disabilities. Also training for staff needs to be addressed specifically, and parents need to be fully informed of this law and their rights to refuse to agree to certain practices. In addition, the rules need to provide more specific guidance on reporting and documenting incidents of isolation and restraint.

Keeping children with disabilities safe from harmful isolation and restraint can be achieved. Families, schools, State agencies and the community need to work together in developing these rules and using positive behavioral supports as an everyday practice.

Sherry A. Wilds is staff attorney with the Disability Law & Advocacy Center of Tennessee.

Back Row (left to right): Ruth Wolery, Frances Lewis, Paula Messenheimer, Felicia Burk, Laura Pollett, Ward Matthews, Lynise Parisien. Front Row (left to right): Amy Biggs, Gaye Carmon, Sheila Moore, Dena Gassner



Photo by Tony Maupin

VOLUNTEER ADVOCACY PROJECT

BY MEGHAN BURKE

Prior to 1975, millions of children with disabilities were either entirely excluded or limitedly included in public schools. In 1975, Congress passed the Education for All Handicapped Children Act, mandating public schools to not only educate students with disabilities but also to provide them with necessary supports and services. Embedded within this law was parental involvement. Congress wrote parents into the legislation in 1975 to ensure that children with disabilities would have advocates in securing their rights to a free, appropriate public education.

This act has been reauthorized several times since 1975 and even renamed in 1990 as the Individuals with Disabilities Education Act (IDEA). Despite other changes, parental involvement has remained and, in fact, been strengthened in the legislation. Unfortunately, there are many barriers to parents effectively advocating for their children with disabilities. For example, the IDEA legislation is vast and dense, and to have a solid working knowledge of it would require parents to stay updated on federal and state regulations and district interpretations of the law. It is also difficult for parents to be assertive, but not aggressive, in Individualized Education Plan (IEP) meetings with the school; the power differential between the parent

and the school, the emotion involved in discussing your child, and the feeling of inadequacy are just a few factors contributing to parents' barriers in effectively advocating for their children with disabilities.

Realizing these challenges, The Arc of Davidson County and The Vanderbilt Kennedy Center University Center for Excellence in Developmental Disabilities (VCK-UCEDD) created The Volunteer Advocacy Project. This initiative trains interested individuals to become special education advocates by providing instrumental and affective support to families of children with disabilities. The curriculum is modeled after a training module developed by Georgia's Protection and Advocacy agency. The first cohort graduated from the program in the Fall of 2008; the second cohort will begin training in Spring of 2009.

The training is an intensive 12-week program resulting in more than 40 hours of in-class time. Reading assignments of relevant articles, law and regulations accompany each class session. Additionally, the participants join two listservs to stay up-to-date about special education changes and to consult with each other about special education advocacy questions. Finally, each participant shadows

7TH ANNUAL TENNESSEE DISABILITY MEGACONFERENCE

May 28 & 29, 2009 | Nashville Airport Marriott

KEYNOTE SPEAKERS:

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FOR REGISTRATION AND STIPEND INFORMATION,
visit www.tndisabilitymegaconference.org
Phone: 615-248-5878 • Toll Free: 1-800-835-7077

a special education advocate at an IEP meeting to better understand the role of an advocate.

The content and style of the training varies to allow each participant to have an in-depth working understanding of special education policy and advocacy. Topics include case study evaluations, interpreting evaluation results, IEP meetings, procedural safeguards, assistive technology, transition, least restrictive environment, behavior intervention plans, disabilities covered by IDEA, legislative change and advocacy skills. For each topic, expert speakers are invited to come in and speak, including representatives from The Vanderbilt Kennedy Center, Support and Training for Exceptional Parents (STEP), the Disability Law and Advocacy Center (DLAC), the Tennessee Technology Access Program (TTAP) and The Arc of Davidson County. Each session involves a lecture-style format with supplementary large and small group discussions and role-play.

There are several desired outcomes associated with the project. First is the instrumental support: the training teaches participants about federal and state special education laws such as IDEA, No Child Left Behind (NCLB), Section 504 of the Rehabilitation Act, and the Family Educational Rights and Privacy Act (FERPA). Second is the affective support: the

advocates learn non-adversarial ways to communicate with the school and to emotionally support the parent of the child with the disability. To achieve the third goal, The Arc of Davidson County links each advocate with four families of children with disabilities who require advocacy services. The advocate then works with each family, for free, to ensure their children receive appropriate educational services.

Fourth, the project hopes to expand this model to be a statewide endeavor. To that end, the Spring training will be conducted in Nashville and delivered via video-conference to Memphis. STEP, The Arc of the Mid-South and the University of Tennessee Boling Center for Developmental Disabilities all will help to ensure this project is a success in Memphis. Eventually the idea is to expand to cover the entire State of Tennessee so all families who need advocacy services have such services available in their area. The last goal involves research about the advocates to determine what they learned from the training and research about the families to see how they benefited from these advocacy services.

This training will be conducted twice each year. For those interested, please contact Meghan Burke at Meghan.m.burke@vanderbilt.edu or call 615-585-1420.

SPECIAL EDUCATION ADVOCACY RESOURCES

COMPILED BY COURTNEY TAYLOR AND MEGHAN BURKE

The following national resources may assist special education advocates and families as they work to secure the best possible educational programs and services for students with disabilities. The list is selective.

Tennessee Disability Pathfinder's database contains a number of education advocacy resources in Tennessee. To view those listings, visit: <http://kc.vanderbilt.edu/tnpathfinder>. Click on the icon "Education", and then click on the link "Education Advocacy".

The **Advocacy Institute** is a non-profit organization dedicated to the development of products, projects and services that work to improve the lives of people with disabilities. The Institute provides research and materials on federal education laws and facilitates workshops that teach basic and advanced advocacy skills for parents and special education advocates. www.advocacyinstitute.org

The **Council of Parent Attorneys and Advocates, Inc. (COPAA)** is a non-profit organization of attorneys, advocates and parents. Its primary mission is to secure high-quality educational services for children with disabilities. The organization assists parents in locating advocates and attorneys through its Web site directory. It provides advocates, attorneys, parents and other professional COPAA members with the practical resources and information they need to obtain effective educational programs for students with disabilities. www.copaa.org

The **Disability Law & Advocacy Center of Tennessee (DLAC)** works to empower, protect and advocate on behalf of persons with disabilities. DLAC is a federally mandated agency funded by the U.S. Department of Health & Human Services, U.S. Department of Education and the Social Security Administration. DLAC provides information and referral; individual, systems and public policy advocacy; trainings and presentations; mediation, negotiation and legal representation. Visit www.DLACTN.org or call 1-800-342-1660.

Disability Resources is a non-profit organization established to promote and improve awareness, availability and accessibility of information that can help people with disabilities live, learn, love, work and play independently. In 1996, the organization received a grant to compile an annotated guide about inclusion and parent advocacy. Originally designed as a buying guide for libraries, this comprehensive resource tool describes 265 books, videotapes, pamphlets and

other materials that can help libraries, parents, educators, child care centers and other service providers to plan for and to implement inclusion. Many sections of the guide may be accessed from their Web site. www.disabilityresources.org/DRMincl.html

The **HSC Foundation** is committed to supporting families and other individuals who are providing care for infants, youth and adults with chronic illness, disabilities, at-risk for disabilities or who have unique health care needs. The Foundation has developed *Partnering With Your Child's School: A Guide for Parents*, which helps parents of children who have been diagnosed with health or mental health care needs to learn about available resources and how to develop a partnership with the child's school. www.hscfoundation.org/whatwedo/familysupports.php

The **National Center for Learning Disabilities (NCLD)** works to ensure that the nation's 15 million children, adolescents and adults with learning disabilities have every opportunity to succeed in school, work and life. NCLD is committed to providing parents essential information so they can take effective action on behalf of their child with a learning disability. *Parent Advocacy Briefs* help parents navigate key provisions of No Child Left Behind and help them to understand areas of the complex law that play a direct role in their child's success in school. Visit www.nclld.org/content/view/290/322/ or call 1-888-575-7373.

The **National Dissemination Center for Children with Disabilities (NICHCY)** is a central source of information on disabilities in infants, toddlers, children and youth. The Center provides information on the Individuals with Disabilities Education Act (IDEA), No Child Left Behind (as it relates to children with disabilities), and research-based information on effective educational practices. At the request of the Office of Special Education Programs at the U.S. Department of Education, NICHCY developed the Building the Legacy training curriculum, intended to assist in the understanding and implementation of the IDEA 2004 Part B regulations. www.nichcy.org/Laws/IDEA/Pages/BuildingTheLegacy.aspx#ThemeE

The mission of **PACER Center (Parent Advocacy Coalition for Educational Rights)** is to expand opportunities and to enhance the quality of life of children and young adults with disabilities and their families. Founded in 1977, PACER Center was created and is

staffed primarily by parents of children and youth with disabilities to help other parents and families facing similar challenges. Visit www.pacer.org or call 1-800-537-2237.

STEP (Support and Training for Exceptional Parents) is a statewide family-to-family program in Tennessee established in 1989 by a grant from the U.S. Department of Education. The purpose of STEP is to support families by providing free information, advocacy training and support services to parents of children eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA) who reside in Tennessee. STEP services are available to any parent or family member of a special education student or a student who may need special help in school (birth through age 22). There is no charge for services to parents. Visit www.tnstep.org or call 1-800-280-STEP.

Wrightslaw is a Web site resource for parents, educators, advocates and attorneys interested in learning more about special education law, education law and advocacy for children with disabilities. The site has thousands of articles, cases and resources about a number of topics, including a section on special education advocacy. Visit www.wrightslaw.com

BOOKS

Better IEPs: How to Develop Legally Correct and Educationally Useful Programs
by Bateman, B., & Linden M. Verona, WI: Attainment Company, 2006.

Special Education Law: Cases and Materials
by Weber, M., Mawdsley, R., & Redfield, S. Danvers, MA: Lexis, Nexis, 2004.

2009 TENNESSEE YOUTH LEADERSHIP FORUM

**Now accepting applications for a free leadership training program
for Tennessee high school students with disabilities.**

June 29 - July 2, 2009, Vanderbilt University Campus

Application deadline: March 16



FOR MORE INFORMATION OR AN APPLICATION, PLEASE CONTACT:

Ned Andrew Solomon, Director, YLF
TN Council on Developmental Disabilities
404 James Robertson Parkway, Suite 130
Nashville, TN 37243-0228
615.532.6556
ned.solomon@state.tn.us



NEWS FROM PATHFINDER

BY CLAUDIA AVILA-LOPEZ & WHITNEY GRIFFIN



Photo by Ashley Coulter

Left to Right: Claudia Avila-Lopez, Carolina Meyerson, and Cecilia Melo-Romie - Tennessee Disability Pathfinder's Hispanic Outreach Team

4TH ANNUAL HISPANIC COMMUNITY CONFERENCE

Tennessee Disability Pathfinder held its 4th Annual Disability Services and the Hispanic Community Conference in November. Approximately 70 individuals from disability agencies and agencies serving Spanish-speaking families attended the conference, which featured presentations and panel discussions regarding the Hispanic Outreach Project and Camino Seguro Middle and West, as well as plans for the replication of Camino Seguro in East Tennessee.

Down syndrome was the focus of this year's event. Two panel discussions were held, which included representatives from the

Down Syndrome Clinic at Vanderbilt, the Down Syndrome Association of Middle Tennessee and the Autism Society of Middle Tennessee.

If you would like to know more about Camino Seguro, please visit the Web site at www.caminoseguro.org and www.caminosegurowest.org. For questions please contact the Hispanic Outreach Team at 1-800-640-4636.

Claudia Avila-Lopez is statewide Hispanic program coordinator at the Vanderbilt Kennedy Center and Whitney Griffin is information & referral services coordinator with Tennessee Disability Pathfinder.

Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the **TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES** and the **VANDERBILT KENNEDY CENTER FOR RESEARCH ON HUMAN DEVELOPMENT**.

HISPANIC OUTREACH PROJECT

Several years ago, Tennessee Disability Pathfinder recognized the need for inclusion and support for individuals with disabilities in the Hispanic community. The Hispanic Outreach Project was developed to reach this population, beginning with an Administration on Developmental Disabilities grant obtained through the Tennessee Council on Developmental Disabilities.

In 2006, the Project began a support group for parents who have children with disabilities. The group's mission is to educate parents about their options and services in Nashville, while providing a supportive environment to express their experiences as a parent of a child with a disability.

"The group has helped me in meeting other mothers with children with special needs," said Fabiola Zapor, mother of a four-year-old son with autism. "It has made me feel welcome and it has helped me in not feeling so isolated and I do not feel I am the only one in this country passing through this experience. When I take my son to therapy, I have recommended the group to other families. I do not want them to feel alone."

The parent support group provides a variety of professional speakers to give resources and educate families. The main focus of the parent support group is to empower the whole family with the tools to build a stronger family unit. When parents are empowered with

information, they are more confident in their choices, not only for their child with a disability but for their other children as well.

"Through the group I have been able to reach the Kennedy Center, which has given me the necessary tools and materials that I may utilize in helping my son," continued Ms. Zapor. "The group has been like a training school for me in allowing me to be able to face the difficult times in my son's daily life."

The parent support group meets monthly, March through December, at Southminster Presbyterian Church at 643 Harding Place in Nashville.

Another focus of the Hispanic Outreach Project is to promote integration within the community. The Project achieves this through the Vanderbilt Kennedy Center's array of programs for families. For example, Journeys in Disabilities: Information & Support for Families is a two-hour orientation that gives parents information, support and resources to help once a family member is diagnosed with a disability. A Families First program provides monthly workshops for parents of children, ages 2-5, diagnosed with an autism spectrum disorder. Additionally, Sib Saturdays provide siblings, ages 5 -13 , of children with disabilities a fun and safe atmosphere to discuss their experiences.

FOR FURTHER INFORMATION

Tennessee Disability Pathfinder

English & Español
(615) 322-8529
(800) 640-4636

TTY/TDD users:
please dial 711 for
free relay service

www.familypathfinder.org

tnpathfinder@vanderbilt.edu



Fabiola Zapor and her son Jesus

Photo by Carole Moore-Slater

TENNESSEE SPOTLIGHT



BY DARLENE WINTERS

"New York, New York" recently became the motivating theme song for Company d. After seven years of weekly classes, long rehearsals, Summer and Winter workshops and performances, performances, dancers were ready "... to be a part of it, New York, New York." The desire for the dancers to perform publicly at a national level, to receive master level dance instruction, and to expand the dancers' aesthetic education and cultural experience "in a city that never sleeps" was part of a vision and became a dream come true in September 2008. It is impossible to rate the best part of the dancers' four-day trip to New York. Every step the dancers took was with excitement and pride, and their confidence grew taller and taller.

The dancers' first night in the city struck a high note with their performance at the Dicapo Opera Theatre, an official Off-Broadway venue, hosted by Luigi Jazz Centre. It was overwhelming to see the Company d dancers step up to a New York audience, deliver a perfect performance and honor Luigi with their reverence to the song "Somewhere".

Company d dancers never stopped moving, taking classes with Luigi, the father of jazz dance, and Francis J. Roach, choreographer and world renowned teacher. Dancers were comfortable and confident taking class with a varied group of New York dance students and professionals. On the third morning, Liza Minnelli, one of Luigi's long time students, shared mirror space with Company d. It was class as usual: stretching, bending and moving to the "rhythm of the body" with

Luigi. However, at the conclusion of class it was a show-stopper when Company d was extended the invitation to perform a piece for Ms. Minnelli and she, in turn, sang and danced "New York, New York" for the class! WOW! What a way to start the day.

Without missing a beat, the dancers attended several Broadway shows, toured the Metropolitan Opera and were invited backstage at performances of *Mary Poppins* and *Altar Boys*. They interacted with the cast and crew and learned about the behind-the-scenes technology of theatre.

Bringing the curtain down on a perfect weekend, the dancers were part of the featured entertainment for the National Down Syndrome Society's (NDSS) 14th Annual Buddy Walk. "The audience was floored by their artistic talents and their chemistry together and the NDSS staff was equally as impressed with their professionalism and graciousness," stated Pamela Sandonato, director of development for the NDSS.

Applause, a standing ovation and a chorus of bravos for the Company d dancers and to our generous supporters who made the trip possible. A grateful heart to the Board of the Down Syndrome Association of the Mid-South who had the confidence that Company d could make this great leap.

Darlene Winters is the artistic director and choreographer for Company d.



Photos by Company d parents



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